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Chair

Mr. Bill Casey

Standing Committee on Health

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● (1550)

[*English*]

The Chair (Mr. Bill Casey (Cumberland—Colchester, Lib.)): We'll call the meeting to order. I welcome everybody to meeting 105 of the Standing Committee on Health. We're going to continue our study on organ donation.

Before I start, I just want to explain what happened regarding having double meetings, because I know that surprised everybody. I checked with Joel, and he said he had emailed everybody and asked if they wanted to do Monday morning or a second meeting on Wednesday afternoon. Four members, I guess, couldn't come on Monday, so he just put the second meeting on Wednesday. That's why we have two meetings today.

Today, as witnesses we have, from the University of Alberta, Dr. Norman Kneteman, professor and director of the division of transplant surgery. From the Canadian National Transplant Research Program, we have Dr. Lori West, director; and David Hartell, executive director. From the Kidney Foundation of Canada, we have Elizabeth Myles, national executive director; and Laurie Blackstock, a volunteer from the national office.

I welcome you all, and I really appreciate your taking the time to come and share you knowledge with us.

We're going to open with 10-minute statements by each, beginning with Dr. West.

[*Translation*]

Dr. Lori West (Director, Canadian National Transplant Research Program): Good afternoon, everyone.

Thank you for inviting me today.

[*English*]

Thank you, Mr. Chair and committee members, for dedicating your time to addressing the many challenges of organ donation and transplantation in Canada.

Like Dr. Kneteman, I am part of medical teams. I am a pediatric heart transplant physician and a scientist in transplant immunology, so I can bring that expertise to our conversation today.

We really applaud your efforts in convening this study on what we can do across the country, as a country, for the tens of thousands of Canadians whose lives can be saved or improved with a cell or organ transplant.

We also thank you for inviting the Canadian National Transplant Research Program to be part of this discussion. We appreciate the importance of the opportunity to inform you about our program and our successes and to provide suggestions for what the federal government might do to increase donations, increase access to transplantation, and improve transplant outcomes.

I think all of us here today understand the life-saving and economic benefits of transplantation. We all recognize the importance of Canadians registering their intent to one day become an organ donor, should the occasion arise. Last month's tragedy in Humboldt certainly was evidence of that, inspiring more than 100,000 Canadians across the country to register online to become organ donors.

However, even with increasing numbers of Canadians being aware of the importance of organ donation, last year in Canada we had fewer than 800 deceased donors and only about 500 living donors. There are 4,500 Canadians officially on the wait-list, and I think it's really important to recognize—and this isn't necessarily generally recognized—that thousands more Canadians could be added to the wait-list. The wait-list numbers really don't reflect the true impact of this problem. This is not a niche area. Tens of thousands of Canadians could benefit from transplantation if there were any hope of finding a donor, so many Canadians who are in need never make it onto wait-lists. I think we need to bear in mind that this is a much bigger problem than what is reflected in those numbers alone.

Our system is falling short of its potential to transform lives in Canada despite the gains that have been made in recent years to return patients suffering from many types of chronic diseases, malignancies, and organ failure back to good health. Furthermore, once a person receives a transplant, we need to optimize the long-term transplant outcomes so that retransplantation isn't needed, which of course further accentuates the difficulties of finding sufficient organ donors so that transplantation can become truly a cure for these diseases.

I think it's important to recognize—and certainly we believe also—that this is solvable. This challenge is not impossible. Canada has the technologies, the people, the resources, the researchers, and the assets to solve this problem. It's not like a problem about which we would say "if only we knew this" or "we didn't know that". This is a solvable problem. We can take much information from places in which there have been successes around the world, and I know we do, and that has been part of the discussion.

Increasing donation and increasing access to transplantation require a strong national partnership at many levels. It starts with having strong and well-funded provincial organ donation agencies, as you heard about on Monday from a number of individuals from different provinces. It requires clear linkages with health charities and with patient groups, creative partnerships with Canadian biotechnology and the pharma industry, and a well-funded national health delivery policy and coordinating agency through Canadian Blood Services, as will be noted by Dr. Kneteman and as was discussed by Isra Levy on Monday. Also critical is a strong and independent national research network that can provide the evidence, the evaluation of evidence and strategy, new knowledge, and new discoveries that will have rapid impact.

To this point, in 2013 the Canadian government, through the Canadian Institutes of Health Research, funded the Canadian National Transplant Research Program, the CNTRP, the goals of which were to put together a framework of research to unite donation and transplantation researchers across the country and across the many disciplines that make up this very complex landscape. Only in that way can we really have high and realistic hopes of moving forward.

This initiative was a result of strong partnerships among several CIHR institutes, including Infection and Immunity; Cancer Research; Nutrition, Metabolism and Diabetes; and Gender and Health; as well as our ethics office and many of our partners who you are hearing from or will have heard from, such as the Kidney Foundation of Canada, the Canadian Liver Foundation, Canadian Blood Services, les Fonds de recherche du Québec - Santé, Genome BC, Cystic Fibrosis Canada, Astellas Pharma, and several others.

What we've created in Canada now is a national research structure that is unique in the world. It unites bone marrow transplant researchers, donation researchers, and solid organ transplant researchers. There is actually no other program like it globally, and it has really become the envy of our international collaborators and partners.

I'll give you a few examples of our major accomplishments over the last five years, because I think they may help inform some of the ideas and proposals that you're thinking about in your discussions in this committee.

The CNTRP has linked researchers at 31 academic institutions and universities across Canada with central leadership provided by the University of Alberta and the Université de Montréal. We've brought together more than 150 investigators, more than 200 trainees, and more than 200 collaborators focused solely on these issues. We're supporting more than 75 tightly interlinked national-based studies that link donation, solid organ transplantation, and bone marrow transplantation together, importantly bringing the science and the clinical research together with health economics, health law experts, ethics researchers, and policy experts. On the hard sciences side, we are linking these with relevant areas in chemistry and engineering. On the humanities side, we are linking them with social scientists, policy scientists, and with machine-learning and artificial intelligence experts. All of these have an important role to play in moving this kind of work forward to have real impact on what we are considering.

We've brought patients and families into our structure as key research partners. Having the public as part of these research efforts ensures not only that we are addressing their priorities but also that we, within a research framework, are accountable to the financers of research. This helps us to evaluate the impacts and propose new projects that are directly influenced by the patient priorities.

We've launched and are supporting the world's largest clinical study in deceased donation with our ODO partners. The study is ongoing and it is transforming donation research in Canada and around the world, with many important international partners.

We've launched national trials using these new—you may have heard about them—"organ in a box" ex vivo perfusion devices. These take organs, and instead of putting them in a bucket of ice and moving them from place to place, keep them alive, functioning, and in much better condition for transplantation. This means that, with the geographical realities of Canada, we can deal with these things and move things around. These are all very creative approaches that are needed in order to really impact these questions.

We're also proposing international strategies to address transplant tourism and organ trafficking, and looking at factors that impair both access to transplantation and outcomes across the full age span, as well as integrating sex- and gender-focused research and, importantly, equity across various diverse groups.

We're addressing issues that impact access and outcomes for Canada's rural, remote, and indigenous populations and other vulnerable groups that are often overlooked.

After five years, the CNTRP has demonstrated the power of creative collaboration, and this has been emulated by several new health research networks both in Canada, such as for antimicrobial resistance and Lyme disease, and importantly, around the world including the British Transplantation Society, the Transplantation Society of Australia and New Zealand, the organization in Germany, and so on, which are asking how they too can build national networks that can have this kind of power on outcomes.

The CIHR and its partners have recently provided support for a three-year extension of our basic infrastructure, but the challenge is to find sustained funding to support this important research and to grow this network.

To this end, we're proposing ideas that were impossible five years ago. We're proposing a larger vision to fulfill every transplant donation, every donation opportunity in Canada, to not miss any, to basically get rid of the waiting list, and to turn transplantation into a cure. We call this our "one transplant for life" challenge, which we've included in the materials for you.

We believe that the CNTRP can help integrate, execute, and evaluate strategies and ideas being discussed by your committee, and we're eager to work with you.

● (1555)

We'd provide abundant multidisciplinary expertise, and we can bring relevant partners to the table to continue to work with you on these issues. We know we could help with some of the examples that were proposed by Ronnie Gavsie on Monday and that will be proposed today, such as a public education campaign, working with CBS to evaluate a national death audit program, and so on.

Of major importance, as I conclude, is support for Bill C-316, which is a real example of the creative nature that's needed to look at why we cannot afford to be stymied by the makeup of our country. We can turn it to our benefit and really use those sorts of strategies to get where we want to go.

In conclusion, we think this is a perfect opportunity to move forward. We're very excited about this committee's attention to these issues, and we thank you again for allowing us to present today.

● (1600)

The Chair: Thank you very much. Your passion shows very clearly.

We're going to go now to Dr. Kneteman.

You have 10 minutes.

Dr. Norman Kneteman (Professor and Director, Division of Transplant Surgery, University of Alberta, As an Individual): Thank you very much.

I'd like to thank you, Mr. Chair, as well as members of the Standing Committee on Health, for the opportunity to speak to the role of the federal government in improving access to organ donation.

We have dealt with a number of challenges for much of the last 30 years. Canada was stuck at an organ donation rate that was less than 15 per million of our population. This was less than half that for some of the other countries in the developed world. Many activities, both provincially and federally, were carried out to try to impact on this, but they were not very effective. I feel this very significantly, because I was involved in many of them.

One of the patterns that became apparent to me through this was that we had several reports—the Volpe report, DM Report, and the Alberta Framework for Action's report. Virtually none of these, however, came with the funding or organizational structure necessary to actually move things forward. So it was with more enthusiasm that I viewed the 2008 proposal to develop an organization within the Canadian Blood Services that would take on this very important role of organ and tissue donation and transplantation.

I certainly don't have to speak to this group about the challenges of working in an area like health in Canada's federal system where, through the Canada Health Act, we have funds flowing to 10 provinces and three territories, and the administration and delivery of the services is the responsibility of each individual province or territory. That being the case, we end up with 10 different organ donation organizations across the country. One of the challenges with this is the patchwork system we have in how we try to carry out this important job.

One of the real accomplishments over the last decade, however, has been the surveys of other countries around the world that had high-performing donation systems. These include the United States of America, Spain, and some other countries from which we have learned some very important lessons that these high-performing systems have in common.

I've listed 10. They start with a system-wide network of donor coordinators and donation physicians—dedicated professionals who actually take this on as a part of their job. In addition, they incorporate a medical record review allowing these professionals to look at each death that occurs to understand if there was a missing opportunity for donations so that they can avoid missing it next time. On top of that, they have online intent-to-donate registries, which, although the legal authorization to proceed from them has moved forward, remain a challenging and long-term strategy.

Legislated mandatory referral of potential donors to organ donor organizations is another important factor. There is also the implementation of all of these types of leading practices, so we need some organization that can help to implement these across the country. This needs to be backed up by professional education, and then, as Dr. West has noted, we need to have the ability to gather information to see how we are doing in these areas. Are we being successful? Where are we missing opportunities? How can we change to improve?

Backing all of that up, we need to have the capacity to carry out this transplant activity. Of course, we also need funding for the organ donor organizations. One factors that is important in all of those countries that have succeeded is a national coordinating agency.

Within the last decade in Canada, there have been many strategies put forward to try to solve these problems. One of the critical points is the understanding that this is an activity donation that occurs largely in critical care units and sometimes emergency departments, so we need to have the critical care physicians onside and very much involved in leading this activity.

We also need the professionalization of our donation services, not the way it was 25 or even 20 years ago when most of this was carried out by physicians who were basically taking extra time, volunteering their time, to try to help out. This is a critical job that has to have professionals who are experts in the area providing this important service.

We need research to inform our health policy and practices as well as to develop national leading practice guidelines and put them in place for each step in the donation process.

Over the last decade, we have made some progress. I think this backs up Dr. West's statement that we can have an impact in this area. In fact, we are seeing some impact already. Over the last 10 years, we've had a 50% increase in donations in the country. That's very impressive, but it's still only part of the way. We still need another 50% increase to catch up to what we might call the standard of care in this area.

● (1605)

The next slide shows how the rates of donation vary tremendously province to province, and even year to year. If we look at this slide, we can see that Ontario has had tremendous growth in the last decade. I think that's been because Ontario has committed significant funding and has built a very effective organization in this area. Unfortunately, that's not the case in all of the provinces across our country, and so we have a bit of a patchwork. We obviously have a tremendous opportunity to improve as a nation in this area.

This next slide looks at some of those factors that contribute to high donor rates, as we've picked up from our evaluation of other countries around the world. It shows what is in place and what is not in place across our country. Now, after 10 years, one would hope that this entire slide would be a series of green dots, showing that we are all doing the things that we already know are effective. As you can see, it's far from that. As a result, when you go down to the bottom, you can see the deceased donor numbers vary tremendously from province to province—as low as nine and as high as 21. We have tremendous variation and still, because of that, we can see a real opportunity to improve across the country.

I bring special attention to three of these areas: the role of professional donation physicians; having systems, by law, that have a mandatory referral of any potential donor; and, implementation of new ideas, like the "donation after cardiac death" that has been put in place over the last decade.

If we look at the top two bars there, we can see that a couple of provinces—B.C. and Manitoba, both with green dots—have put these processes in place. I don't think it's coincidental that if you look at the bottom line, you can see that the number of donors over a five-year period increased 76% in British Columbia and 89% in Manitoba. Unfortunately, not all the provinces have had the same performance over the last five years, which points out a real opportunity for improvement.

As I mentioned, donation after cardiac death is a form of organ donation that was, in fact, the first way it was always done, before the development of the so-called brain death criteria. This has come back as another alternative. As you can see, Ontario again has led the way with the very effective development of such a program. You can see that it's now contributing seven donors per million each year. B. C. is close as well. Many of the other provinces, including all those across the Prairies, are just getting started.

This slide, perhaps better than any of the others, demonstrates the marked variation across the country. In Ontario, as I mentioned, one area in which they really have invested is the implementation of donation physicians across the province. As you can see, there are 66 donation physicians in the province. That's five per one million of population. In contrast, I might point to my own home province of Alberta with two, and Saskatchewan with zero. We have tremendous variations across the country, which is not optimal by a long ways.

To summarize, we can see that we have the ability to impact this area. We have increased our donors by 50% or 60% over the last decade. We have seen some of the major factors that have been important in that. We are now into at least the top 20 in the world, but we can do a lot better. It's clear that local, provincial, and national programs have all contributed to some of this success. Several of the provinces that have invested and built systems and agencies that take this job on and do it well have seen very substantial improvements in the ability to deliver care. This is not just in delivering donations, because, of course, this is what really determines the access that patients in our province have to life-saving treatments like liver or kidney transplantation; this is really the essential part of the formula that allows a surgeon like me to help these people who are in critical need.

While the progress that we're seeing is encouraging, much more work is needed in Canada to bring us closer to the best. Again, provinces that have implemented these features of high-performing donation systems are seeing the greatest results, demonstrating that we can improve across the country.

Where can a national system add to performance? Certainly, there are areas in which the entire Canadian population of donors is needed to address a problem effectively.

● (1610)

In addition, I think we can have a national system that can help support the implementation of strategies that have been proven to help donation, but do it across all the provinces, not just some. We need to be able to build a national database of activity and outcomes for both organ donation and transplantation that can support decision-making and research. We also need stability and long-term funding for a national agency that would support and guide donation and transplantation.

What are some of those areas in which we need the entire population to address a problem? There are several, and first I'll talk about the situation of an individual who is exposed to either a blood transfusion or childbirth. When we're exposed to the antigens, the proteins of another individual, our immune system reacts as it should. It creates antibodies against them, just as it would if we were immunized or if we were exposed to an infection. The challenge is that this then creates a situation in which we are effectively immunized against receiving a transplant.

There are people in our population who may have this antibody level against 99 out of 100 people in the population, making it extremely difficult to have an HLA match that would be successful for them. It's only when we can look at a group of millions of potential donors that we can overcome this problem.

In addition is paired kidney living donor exchange. If, let's say, a husband wishes to donate a kidney to his wife and he is blood group A and she is blood group B, that won't happen; that won't work. However, if we can find another couple who has the opposite, they can swap and that can work well. These two programs that have been active for the last three or four years have allowed 1,000 kidney transplants to be carried out in Canada that would not have been done otherwise.

We also have other areas for which I have illustrated how we can support implementation across the provinces to build a national database so we know what we're doing. Unfortunately, if I want to do research right now on how to do transplantation better, I have to go to the United States to look for that information.

In closing, I think it is important that we take the agency that has been put in place and given this job.... There is the organ donation and transplant section of Canadian Blood Services, but unfortunately at present it still struggles with a very limited budget that is renewed every three years on application. I think we need much more solid and stable sorts of funding for this type of a national agency.

Thank you so much for your attention. I look forward to your questions.

The Chair: Okay, thanks very much for that.

I hate to cut you off, but we're anxious to get to questions.

Now we go to the Kidney Foundation of Canada for 10 minutes.

Elizabeth.

Ms. Elizabeth Myles (National Executive Director, The Kidney Foundation of Canada): Thank you, Mr. Chair, and committee members. On behalf of the Kidney Foundation of Canada, I am very pleased to be here today with Ms. Laurie Blackstock, who has a family member on dialysis due to kidney failure, and her husband and her aunt were both deceased organ donors. I'll speak a little bit first and then she'll speak about her experience after.

I would like to start by thanking you for your invitation to appear as a witness today. In spite of the advances in the number of organ transplants over the last few yeas, Canada is still significantly short on the number of organs available to meet the needs of thousands of Canadians awaiting life-saving transplants. There is an urgent need to improve our organ donor and transplantation system.

About 4,500 Canadians are waiting for an organ transplant, and more than 75% of those on the waiting list are waiting for a kidney. There are far more people waiting for transplants than just those on the wait-list. Of the 22,000 Canadians whose kidneys have failed, who require dialysis to live, only about 16% of them are on the transplant wait-list. Access to a transplant is a matter of life and death for people with kidney failure.

The other treatment option is dialysis, which is a life-sustaining form of therapy. Dialysis saps away patients' time, energy, quality of life, and eventually, life itself. The five-year survival rate for someone on dialysis is less than 45%, which is a worse prognosis than that for many cancers. In contrast, the five-year survival rate for someone with a deceased donor transplant is 82%.

Gwen, a nurse and mother of two, describes dialysis as more like life-support than living. She describes kidney disease as having eroded her life, thereby robbing her of her profession, her energy, and her ability to think clearly, until all that she was left with was "a tired, painful, small, isolated life". After her kidney transplant, she got her life back and is living a life filled with creativity, laughter, and meaningful work.

In addition to giving a patient survival and quality of life, transplants can save the health care system significant money. The total annual cost of dialysis ranges from $56,000 to $107,000 per patient. The cost of a transplant is about $66,000 in the first year and about $23,000 in subsequent years. Therefore, the health care system can save up to $84,000 per patient transplanted, annually.

In spite of all the benefits of a kidney transplant over dialysis, the number of people waiting for a kidney transplant is roughly double the number of kidneys transplanted. There were 1,731 kidney transplants in 2016. The median wait time for a kidney transplant is four years, ranging from 5.7 years in Manitoba to three years in Nova Scotia. Every year kidney patients on the wait-list die while waiting for a transplant or are removed from the wait-list because they are too sick to undergo a transplant. This is the tragic reality for thousands of Canadians who suffer from kidney disease as well as for their families.

The biggest tragedy is that many of these deaths could be avoided if improvements were made to the donation and transplant systems across the country. In an environment where the supply of donor organs is low and demands are high, missed opportunities for donation are a matter of life and death. Only 2% of hospital deaths meet the criteria for deceased organ donation, yet only one in six becomes a deceased donor. Donor organs are rare and precious. Each deceased donor donates four organs, on average, so every missed potential deceased donor means depriving at least four Canadians of a life-saving transplant. People are needlessly dying because of system failures for organ transplants.

The federal government can improve Canada's organ and tissue donation and transplantation system by implementing a national strategy. Oversight is required to ensure that every potential deceased donor is identified and has the opportunity to save lives through organ donation and so that every person awaiting transplant has equitable access to organ transplantation across the country.

● (1615)

This includes the implementation and monitoring of best practices, public and professional education, and the development and coordination of an advanced interprovincial organ-sharing system.

The federal government can also improve the system and save lives by promoting living donation through public awareness and reducing barriers for the donor and recipient. This includes implementing practices to reduce the amount of time it takes for a potential donor to be screened and continuing to support living donors and living donation programs such as the kidney paired donation program.

Finally, the government can support research to improve graft outcomes and the availability of organs for transplant for more people with kidney failure.

Thank you.

Ms. Laurie Blackstock (Volunteer, National Office, The Kidney Foundation of Canada): I'm here to help personalize the need for a national system. As Elizabeth mentioned, my father lives on dialysis, and last year my husband became a deceased organ donor.

To help support my father, my brother has quit his job as a teacher and moved home to the family farm to be there for him. He's not allowed to live alone. He travels about 30 minutes one way to a hospital, spends four hours at the hospital each time, and then travels back home. As a result, his energy is depleted. He mostly watches TV now and reads books instead of being out on the tractor and mowing the lawn.

My husband's story is harder to tell. Last year I came home from a winter camping workshop and the house was dark. I came in and I could hear banging on the second floor. I went up the stairs and I found my husband in non-stop seizures, unconscious. He was rushed to the local hospital, where he had a heart attack in addition to the seizures. The main thing was that they brought him back to life. He was living. They got him to the Ottawa Hospital, where he was sent to the ICU and put on life support. If he hadn't lived long enough to reach the ICU, he would not have been able to be an organ donor. Of course, I wasn't thinking about that at the time; I wanted him to live.

After about two days, it was clear that although the ICU doctor and nurses did their best to stop the seizures, my 57-year-old seemingly healthy husband probably would not survive. That's when they began to speak to me about organ donation.

The timing was right. He told me that he had checked the donor registry. He knew that Stephen had consented to organ and tissue donation. At that moment, surprisingly Stephen's mom and I were lifted up by this news. We could tell we were going to lose Stephen. There was very little chance that even if he survived he would function, so this opportunity was a gift, and it immediately felt like a gift. It gave us something to cling to.

The doctor explained that there was a Trillium Gift of Life coordinator in the other room ready to speak to us if we had already made our decision or if we had any questions. He said explicitly that he and the coordinator would never be in the same room at this stage so that we didn't feel outnumbered or pressured to come to a positive decision about donation. For me, that was important.

He stepped out, Stephen's mom and I conferred, and then the Trillium Gift of Life coordinator entered at our request when we were ready. She explained that if we agreed to Stephen's wishes, it would mean he would be on life support for an extra day. They'd try to get him off as quickly as possible, but it would take at least a day to bring together the transplant team and the potential recipients to begin the matching.

At that moment, knowing that my father was on dialysis, I wondered if one of Stephen's kidneys could be transplanted to my father, and wouldn't that make a great movie? But life isn't a movie, and my father was not eligible for a transplant. Of course, we were still thrilled to know that in another day probably several families—up to eight—would be utterly joyous, while we continued to grieve. Although we were in despair at our loss, we didn't want to deny other families the possibility that their loved one could be saved and live a much healthier life.

A week after deciding that I'd be an advocate and an educator, I received the best thank you card ever. This is from the young man who received a double lung transplant and is now breathing through my husband's lungs. He said he was able to spend Christmas at home with his family for the first time in three years. He's building skills that he couldn't have otherwise, after many more years in the hospital. What touched me most was that he said he thinks of his donor family every time he breathes. His last line was that the word grateful couldn't begin to describe how he felt. He thanked us and said that we had saved his life.

● (1620)

I'm here to emphasize that organ and tissue donation doesn't just help the recipients and their families. It doesn't just reduce the tremendous cost of long-term kidney treatment. It can also be an incredible gift to bereaved families like mine, because when presented gently and ethically, at the right time, when there's little or no hope of a loved one's survival, it is a gift. Knowing that five people's lives probably improved dramatically with Stephen's lungs, kidneys, and corneas doesn't change his death and the intensity of our grief, but it gives us moments of relief.

Stephen lives on through those five people.

● (1625)

The Chair: Thank you very much for sharing that with us. There's no other way we could ever appreciate or hear or understand that, other than hearing it from you. It's quite a story. It means a lot.

We're going to go to our seven-minute round of questions, starting with Mr. Oliver.

Mr. John Oliver (Oakville, Lib.): Thank you, Chair.

Thank you very much, Laurie, for your testimony and for sharing that very personal story, how it has impacted your life, and how it has impacted others around you. I notice you've been very busy with the Cancer Society, Gift of 8, and different campaigns. You've been a real champion for different causes, so thank you for all you've been doing. It's great to meet a Canadian like you, for sure.

We've been listening to testimony from other groups as well. As a committee, we ask what we can do at the national level? We can write a recommendation to the minister and to Parliament, around strategies. Here's what I have picked up so far.

Number one, develop and implement a sustained national multimedia campaign to promote donation.

Two, increase the opportunities for donors to identify themselves as donors. At the federal level, we heard we could be using tax forms. Besides ServiceOntario, we could use Service Canada and various forms like that.

Three, promote enhanced interprovincial sharing of organs, particularly for people with more difficult and special circumstances.

Number four came out of what I heard today as much as from before. It sounds as though we have a national coordinating agency, but it may need to be more robust. It should be doing best practice identification, and maybe even implementation strategies. I am astonished, to be honest with you, at the variation across Canada by province. That tells me that provincial leadership is essential. When I look at the differences between Ontario and Nova Scotia versus Alberta, Saskatchewan, Manitoba, and Newfoundland and Labrador, there is a huge variation. That's where those best practices and strategies could be brought to bear, for sure. There's also a need for a national database for research, which I'm assuming could be operated by a national coordinating agency.

The last one—Laurie, you hit the nail on the head again—was what we heard from the Trillium Gift of Life witness at our last meeting. I used to run a hospital, and I know that in just the last two or three years, in around 2013-2014, the Gift of Life model changed. It stopped being left to a doctor or a nurse in the ICU or the emergency department to talk to the family. Those people are not geared to organ donation conversations; they're geared to life-saving strategies, so making that switch was almost impossible.

There's now a requirement in Ontario that you must report certain brain deaths to Trillium Gift of Life and pass the information on. Trillium Gift of Life then handles the conversation, and if it's acceptable to the family, an on-the-ground organ retrieval team comes out and works with the family and extracts the donated tissues.

When I look at the numbers in Ontario, that is the real boost that has happened—that really proactive approach by Trillium Gift of Life. I really want to push that need for support at the hospital in emergency and in the ICU by the provincial equivalents to Trillium across Canada, and the on-the-ground team that's ready to come out to the hospitals and assist the local caregivers.

That's my list.

Is there anything else you'd want to add to that, in terms of our coming up with recommendations?

● (1630)

Dr. Lori West: I think the case should be made regarding the importance of a continued national research framework that can drive some of them. I think you're correct that it's not just a matter of having a national database that can be housed and that has been created by CBS and is very helpful; the many levels of multi-disciplinary research that really impact all of these aspects are, I think, really crucial.

Mr. John Oliver: Can you be more specific? What areas would you see the national research being needed in?

Dr. Lori West: Taking the framework that has already been well established and has been successful and funding it in a sustainable way—

Mr. John Oliver: Yes, sorry, I had funding down here.

Dr. Lori West: The most logical way to do that is to continue to do it through CIHR , because that has allowed this to develop that way. This is not part of CBS, but it works very closely in successful partnership with CBS, and that works really well. I think having a sustainable future for this kind of research makes perfect sense and could be done. This is where Canada leads the way already.

Mr. John Oliver: Okay, it needs sustained funding.

Norman, do you have anything?

Dr. Norman Kneteman: I'd make two points. One, as I pointed out, is that mandatory referral of potential donors is going well in Ontario. These areas that we talked about, which are so important—and you pointed them out—do not happen across the country. Two, having donation professionals involved in the discussions and the questioning is also critical. The challenge, of course, is that no provincial organization, no matter how well meaning or well funded, is going to be able to take the lead to do this across all the other provinces, so we need some national organization that is empowered and required and funded to do this.

With regard to the national database, the Canadian Transplant Registry that CBS has built is in place; the computer system exists. The challenge is how we get the information into it. In Canada, all the reporting and transplant and donation in our history has been voluntary, and because of that, it's full of defects; it's not reliable. We have to get beyond that, and we need to be thinking about how we are going to fund the activity of getting the information into the database so the professionals, the researchers Lori's talking about, have something to work with.

I think those two things as a start would be very important and could have a real impact.

Mr. John Oliver: It's hard to get your mind from that high-level research data compilation material to what really happens in the emergency room at three in the morning when somebody comes in with a traumatic head injury, and how you have that conversation in that space and time. It's the on-the-ground part and it's also the broader registries.

Dr. Norman Kneteman: Certainly, I don't think it's for a group like ours to try to get down to that level of exactly what steps need to be done day by day, but having the system in place that can do these things, I think, is the critical factor.

Dr. Lori West: Mandatory reporting is a key element that works in every jurisdiction.

Mr. John Oliver: Is there mandatory reporting across Canada now?

Dr. Lori West: Do you mean the need for mandatory reporting?

Dr. Norman Kneteman: It's all voluntary.

The Chair: Okay, we have to go to Mr. Webber.

Mr. Len Webber (Calgary Confederation, CPC): Thank you, Mr. Chair.

I again want to thank the committee for allowing this study to happen here today.

I also would like to thank our witnesses here today, our presenters, for coming all this way, in particular, Dr. Lori West for mentioning in her presentation Bill C-316, which, if passed, would allow Canadians to indicate their desire to be organ donors through their annual tax filing.

Also, thank you, Laurie Blackstock, for your story and your volunteerism and your advocacy, and thanks to your husband as well for his great gift of life.

Mr. Oliver did a very good job of summarizing what we have been hearing the last couple of days with regard to what we can do as the federal government to help support the organ and tissue donation system here in Canada. The additional comments you made here today are very helpful.

I do have some specific questions really quickly here.

One is to you, Dr. Lori West, regarding your presentation and the document you provided. First, thank you for your great work in research as well. You mentioned here that you have a solid track record of success, which you do. One thing in particular, I noticed here, is that you uncovered the legal, social, institutional, and professional challenges that contribute to the family veto of previously registered intent to donate. I would like you to elaborate on that. Are we seeing many situations in which families are vetoing the wishes of the potential donor?

● (1635)

Dr. Lori West: I think everyone realizes what a complex landscape this is. There are many factors, both large and small, that contribute to our ongoing issues with organ donation. This is one example of how something that we originally thought and were told was not a very important obstacle to increasing donation has, in fact, turned out to be very important, quite numerous, and quite frequent.

This is work done through combined efforts and led by Tim Caulfield at the University of Alberta. Despite the fact that in examining the legal landscape in every province across the country about the requirement for permission for what happens when you sign up to be an organ donor, and despite your entering into a legal event by signing an organ donor registry, your family can override your own wishes. They could never decide that you can't donate your fortune to a cat when you die, but they can easily say they don't support organ donation by an individual who had a legal entity saying that they wanted to.

This is actually much bigger and more common than we had previously known. Again, it's one factor in many. However, these are the things we can potentially address by looking at each one of these obstacles to donation.

Mr. Len Webber: Dr. West, can we not trump the family wishes, then? If it is a legal binding document that a person has signed which says, "I want to give my organs upon death", why is the family trumping this? Cannot the doctors or the government say that they are sorry, but that they will be doing this?

Dr. Lori West: Across the country in every province, there's this split between the legal situation and the health delivery aspect of it. In every province, the way the systems are set up requires requesting and getting permission for this. There's a real disconnect here, and that can be worked on to really streamline that across the country and to overcome—

For example, the conversation could not be, "We're asking your consent", but rather, "Your loved one"—as we heard here —"indicated that this was important to them and they went to this effort. We are here to help make that happen."

Mr. Len Webber: Thank you.

I have a quick comment on retransplantation. I have a good friend who's had a double lung transplant. He's coming up to 10 years now. Hopefully he'll last another 10 years, but it's not very common. Is it correct that there is a lifespan for organ transplantation? What research are you doing to improve the longevity of transplanted organs?

Dr. Lori West: The longevity and the transplant outcomes vary a lot depending on which organ is transplanted, and that's a very complex equation. Lungs have probably the most difficult pathway.

There are increasing numbers of individuals whose transplanted organs are failing for reasons that we understand a bit about. We understand more and more every year because of the research that goes into understanding that. It's having an impact on how we can address those complex problems and on trying to decrease the need for retransplantation, which of course will then have an impact on the waiting list.

Mr. Len Webber: Thank you.

Quickly, because I have only so much time, Dr. Kneteman, I have a question for you.

I am unable to give blood right now, because I recently had a trip to Africa. For a year I can't give blood. My daughter has had malaria, so she can never give blood again. There are many other instances of Canadians who cannot give blood because of certain situations or lifestyles. What happens now if I get in accident, God forbid. My family will, of course, allow organ donation. Will it happen?

Dr. Norman Kneteman: There's a major difference between a blood donation and an organ donation. The big difference is that in the situation of an organ donation, there is nowhere near enough supply to meet the demand, whereas with blood, we're much closer to being able to supply the need. You certainly hear about shortages of blood, and those are important, but they're usually intermittent and temporary and in one location.

We have come a long way in the last decade in understanding how significant the risks are from various different possible infections an individual may have. Even in the situation of an intravenous drug abuser who may have hepatitis C, we now understand what the risk is to the recipient. The medical team has the ability to come up with the decision and make a recommendation to that individual. The individual, of course, will make the final decision, but we know in that situation, for example, that we can transplant that patient and treat them with very effective anti-hepatitis C drugs afterwards.

In many of these situations we have much better information about the risk involved, so your family would be presented with that situation, as would the potential recipient, and they can make a decision to go forward.

● (1640)

Mr. Len Webber: I see. Great. I need to go very quickly here.

From the map you have here showing our implementation of donation physicians in Canada, it doesn't look as though Alberta is doing a very good job here right now. I do want to ask about the hospitals in Alberta. Are all the hospitals in Alberta prepared for any situation that may arise in which there's an opportunity to harvest from an individual, or are we giving up significant opportunities to take advantage of this?

Dr. Norman Kneteman: I think if you look at that slide as well as at the other one that shows the rates of donation, you can see that Alberta trails well behind Ontario. There's no reason that it should. But one of the differences—in fact there are several—is the fact that we basically have only two professional donation physicians in the province in a situation where we understand we need many more.

The bill that came forward to develop an agency in Alberta basically has started but has not gone nearly far enough in many different areas to try to address questions just like that one.

The Chair: Okay, thank you very much.

Now we go to Mr. Davies.

Mr. Don Davies (Vancouver Kingsway, NDP): Thank you, Mr. Chair and witnesses.

Dr. Kneteman and Dr. West, my understanding is that current regulations concerning the exclusionary criteria for individuals who cannot be organ donors include men who have had sex with men in the preceding five years. What, if any, scientific evidence suggests that men in sexual relationships with other men should be excluded from becoming organ and tissue donors, and do you believe that this criteria for exclusion should be changed?

Dr. Norman Kneteman: I think it is an important discussion and I think it's important to understand what those criteria actually mean. The criteria basically are things that increase the risk. They don't necessarily prohibit donation. That is an important difference. As I said to Mr. Webber, those pieces of information will say that this individual is in a situation we recognize as having higher risk, and as I say, it could be even something as serious as intravenous drug abuse.

We still have the opportunity to go in—we can do it very effectively—and do what's called nucleic acid testing. This can tell us in fact within a period of several days whether someone has been exposed to hepatitis C or HIV or different agents like that. The donation physicians and the transplant physicians can discuss that information with the potential recipient, who basically has an opportunity to go forward.

Only, for example, if someone was actually tested and found to be HIV positive would it mean, in the vast majority of centres, that we would not go forward.

Mr. Don Davies: It's not an absolute prohibition.

Dr. Norman Kneteman: It's not an absolute prohibition. It's basically a reflection of increased risk that we have to understand, and we have to explain that to the potential recipient, because they of course need to be able to give informed consent to go forward with that transplant.

Dr. Lori West: Just to add to that, I remember those discussions when that legislation was enacted. Remember that when I speak to a parent of a child who needs a heart transplant, there's a 100% risk of dying. They're facing 100% risk that their child will die without a transplant. Really, as Dr. Kneteman says, this is about weighing risks and it can't be absolute. It has to be relative.

Mr. Don Davies: I just want to clarify, because we have information from the analysts and from the Library of Parliament. I'll read it to you:

> In addition, to general organ and tissue donor exclusion criteria included in Safety of Human Cells, Tissues and Organs for Transplantation Regulations, Annex E to the general standard expands on the category of individuals at risk of infection with HIV and viral hepatitis to include men who have had sex with men (MSM) in the preceding five years.... Consequently, these individuals are required by the regulations to be excluded as organ and tissue donors.

Im just trying to clarify. This information suggests that they're excluded. Your testimony for this committee is that they're not excluded but rather it's discretionary. I'm just trying to clear that up.

Which is it? Are they excluded or can it happen depending on the discretion of the physician?

Dr. Norman Kneteman: My experience in practice is that it can and does happen with the understanding that this presents an increased risk that has to be discussed with the potential recipient.

Mr. David Hartell (Executive Director, Canadian National Transplant Research Program): We've done research, and we've published guidelines over the last couple of years explicitly stating that this is something that can be done and that we want to make sure that these donors are captured.

● (1645)

Mr. Don Davies: Thank you.

I want to get to funding.

Dr. West, my understanding is this isn't perfect but I understand there's funding that's received for research through the Canadian Institutes of Health—

Dr. Lori West: Research.

Mr. Don Davies: —Research—$14 million in general—but that there's some vulnerability to that funding. There's $3 million that has been allocated for the next three years, but I understand that federal funding for that research is not certain.

Can you elaborate on that and on what you need?

Dr. Lori West: Yes. The CIHR and the partners that I named provided, through a mechanism through CIHR, an initial $14 million for a five-year program. We're at the end of that now. That funding, which we leveraged into nearly $40 million through creative partnerships, is coming to an end now. That's what has been responsible for helping us achieve our success.

There was no mechanism for automatic renewal under that particular program. However, based on the success of the program and the many successful outcomes, they have put together a three-year period to sustain limited financial support for the infrastructure of the CNTRP research framework. It's only $3 million over the next three years.

Unless we have a new mechanism of support for this kind of a research framework, then we'll not have funding to go forward after that.

Mr. Don Davies: Okay.

I want to get your quick opinion on presumed consent. We heard some testimony at the last meeting about the desirability of moving to some form of "presumed consent" model.

Quickly, to each one of you, are you a fan of presumed consent? Should we consider such a system?

Dr. Norman Kneteman: Presumed consent has been in effect and has perhaps been very effective in a number of countries, especially in Europe. Many of those countries had histories such that they have a bit of a different past. North America has a legal system based much more on the individual's rights, and that has been a big part of the push to maintain the discussion with each individual. Now, I'm not saying that's the way it has to stay, but I think that's part of how we got to where we are.

In reality, as far as I'm concerned, if the majority of our population is in support of an idea like that, I would basically be perfectly happy to see us move forward.

There is the potential, obviously, to alienate or anger people on the other side of the fence, so that's been part of the concern about moving in that direction. You could actually take some people and because of the feeling of push—

Mr. Don Davies: Or backlash—

Dr. Norman Kneteman: —with presumed consent, you could have a backlash. That's the reason, I think, there hasn't been great enthusiasm to leap forward. But, in reality, the numbers in polls have steadily, over the years, improved in terms of the direction of presumed consent; and it's actually over 50% now in Canada.

Dr. Lori West: I would fully agree with what Dr. Kneteman has said. I think this is one piece of a complex puzzle, but each of these should be considered.

Some of the things he spoke about, such as donation specialists, even in countries that have presumed consent —Spain being the highest performing in the world—will tell you that presumed consent has been only one element of it. This has been well shown. Putting forward structural things such as national death audits, mandatory reporting, and donation specialists has really made the transformation possible in their countries.

Of course, in Canada it's a different jurisdiction, but we need to adapt to that for success in our own country.

Mr. Don Davies: Thank you.

The Chair: Time is up.

Now we go to Ms. Sidhu for seven minutes.

Ms. Sonia Sidhu (Brampton South, Lib.): Thank you, Chair.

Thank you to all the witnesses for being here.

A few weeks ago I met Ms. Blackstock. Mr. Webber and I co-hosted a reception on organ and tissue donation by Canadian Blood Services.

Thank you for sharing your story.

Thank you, Mr. Webber, for that session.

My question is to you, Dr. West. What are the conditions in which someone passes away that enables them to qualify as a deceased donor, such as a cardiac death? When can a patient not donate their organ?

Dr. Lori West: I'm not sure I understand your question exactly.

Ms. Sonia Sidhu: What are the conditions in which someone passes away that enable them to qualify as a deceased donor?

Mr. David Hartell: In looking at deceased donation, we need to realize that this is an incredibly rare opportunity. The conditions under which someone can become a deceased donor are the result of probably only 1% of the deaths that happen per year in Canada. About 270,000 Canadians die per year and to be considered a potential deceased donor, you have to die in a hospital, in an ICU unit, while on a ventilator, and without any chronic complications that would prevent you from being a donor. We realize that it is an incredibly rare opportunity and that's why missing any potential donor, to us, is a public health concern or something that should never happen in a hospital, although we know it happens all the time. For example, Lori mentioned that we had just under 800 deceased donors in total in Canada last year and we think we are potentially missing thousands of donors every year that do not get identified.

Part of the problem is that there are no repercussions for the hospital if it misses a donor. There are no repercussions for the unit if it fails to identify a donor. In our work with Canadian Blood Services, we've been looking at the potential mechanisms we can put in place and trying to understand the system changes we can make to better identify these donors. If we could go from 800 donors to 2,000 donors a year, that would have a transformative impact on our ability to transplant patients.

Working together with Canadian Blood Services, we are able to look at different ways of understanding where the critical barriers are in identifying donors and how to never waste a potential opportunity. Let's start using all of the organs that are offered and presented. Dr. West was talking about these organ-in-a-box devices that allow us to actually take an organ that would have normally been thrown in the garbage and put it on the machine to repair it, do surgery on it, and manipulate it, in order to use it to save lives. We're looking for every opportunity to increase donation and we want to look at the system to see where there are challenges so that we can start identifying more donors.

● (1650)

Ms. Sonia Sidhu: Thank you.

Dr. Norman, can you elaborate on the idea of mandatory referral for potential donors?

Dr. Norman Kneteman: In some Canadian provinces, we have moved to this system of mandatory referrals for potential donors. Whenever someone suffers from either a severe injury to the brain or a stroke or participates in some activity that basically results in the fact that they will almost certainly die or are already dead, then the law requires that the critical care doctors or the emergency department doctors who are looking after that individual must report that potential donor to the organ donation organization—Trillium in Ontario or BC Transplant in B.C.—so that they can be considered for donation. If the case is such that they can go forward, then they will have a discussion with the family. Unfortunately, that is not in place in all provinces in Canada.

Ms. Sonia Sidhu: Thank you.

You also mentioned patient family research partnerships. How can we implement those?

Dr. Norman Kneteman: Sorry, can you clarify that question?

Ms. Sonia Sidhu: I'm referring to patient family research partnerships in rural and remote areas. How can we implement that research in more provinces? In Saskatchewan and Manitoba, it's very low.

Dr. Norman Kneteman: I didn't want to make the case by pointing fingers at individual provinces, but in reality, we have to recognize that among different provinces across the country, we have very different levels of commitment, funding, and development of the various aspects that we know are effective. Again, this needs a countrywide approach—a federal or national approach—so that we can understand which areas are not moving forward and all of the areas that can help, and so that we can provide them with whatever assistance is necessary to get them to overcome their challenges getting those systems in place. Realistically, right now it's not really anybody's job to look across the country and say, "Okay, this is not happening in these provinces. How do we actually get it to happen?" We need to make that somebody's job and we need to fund them to do it.

Mr. David Hartell: In terms of addressing the patient-researcher partnership, one of the things we have done, I think successfully in our network, is to look at ways to bring patients and families as co-researchers into our studies—not as participants, not as people we are studying, but as people who are helping us be team members, to help us design our studies, evaluate our studies, and set the research priorities. They participate in our peer review.

We have looked at patients and families as having experience. Lori talked about her experience of going through the donation process. We have a number of family members who have gone through the deceased donation process and are helping to inform our research studies, so that we are asking the right questions, engaging with families in the right way, and designing the research in a way that will have an impact and address concerns of patients and families.

● (1655)

Ms. Sonia Sidhu: Thank you.

I have another question, and anyone can answer.

When we talk about medical professional donor teams, is there any special training that we need to do that?

Dr. Norman Kneteman: Basically, there are a lot of skills that are important, and I think systems to develop that sort of training are in the process of being developed in the country. They are a long way from perfect, but we do have work going in that direction.

Some of the physicians who are involved in these areas have travelled to other countries to see how the systems work there. Usually, of course, they will pick a country where the system works very effectively, so many have gone to Spain or to the U.S., to particular OPOs in the U.S., where their results are very good to try to learn that.

It's one of those areas in which it is important to have some support for the people who become interested in it. We still have a ways to go to say we are ideal in that regard, as well.

The Chair: The time is up. Thanks very much.

Now we go to our five-minute round, and we start with Mr. Aboultaif.

Mr. Ziad Aboultaif (Edmonton Manning, CPC): Thank you very much.

Thanks, Chair. It is nice to see so many familiar faces.

Dr. Kneteman, first allow me to personally thank you and your medical team for all you have done for my family. For those who don't know, my son Tyler is a three-time liver recipient. One of them was donated by me, and the rest came from deceased donors. Dr. Kneteman led the surgical team in our case, and I would like to say I'm eternally grateful. Thank you.

In 2016, as you probably know, I introduced Bill C-223, which sought to create a national organ donor registry. Unfortunately, it was defeated by the government at second reading in the House of Commons due to unneeded partisanship. I must mention that the chair supported me on my bill, against the government's will. Thank you.

I'm pleased to see this committee finally deciding to study such an important topic that is close to my heart and mind through personal experience, and which led us as a family to finishing with our pain of almost 20 years. We can only be grateful to the medical teams and the families who donated. We still don't know who they are. They came forward and gave us two additional opportunities to the one that we started ourselves.

We know that about 260 Canadians died in 2016 due to unavailability of organs. We also know that about 4,492 Canadians were on the waiting list. The waiting list can go for four years. I hear some stories about waiting lists for kidneys that go for eight years, maybe ten years, which is ten years with no quality of life. We know how unproductive that is for the patient, the families, and the community in general.

It is safe to say that we need a more coordinated effort among the provinces, and a national awareness effort and program—I call it a registry—at some point.

For my question, I'd like to start with Dr. Kneteman, and all of you can elaborate or answer.

First, are you aware of how many organs from deceased donors we do not get the opportunity to benefit from? Based on that answer, do you feel that we need a national organ donor registry that would link all the provinces and basically, if you don't want to say "obligate", at least put everyone under one responsibility to act and work together?

Dr. Kneteman, if you would like to start answering those questions, I'd be grateful. Thank you.

● (1700)

Dr. Norman Kneteman: The situation, I would say, is that when the family consents to donation, the donation and the transplant system will make every effort to utilize every organ that can possibly be used. There are many situations in which the organ in question may be damaged, either by disease in the recipient ahead of time or by events that happened around the time of death, and it's not felt to be suitable, so not every organ can be recovered from every donor, but we do certainly make an effort. If there's an organ that can't be placed, for example, because the HLA is not a match in the province of Alberta, we would then try to match that into British Columbia or any other province across the country. We do certainly make efforts, and if we can't place it in Canada we will in fact contact the U.S. to see if it can be placed there. We make every effort to minimize the loss.

By far a bigger problem is the up front.... In fact, there are too many cases in which the potential donor is not recognized, or if they are recognized, that fact is not brought forward to the organ procurement organization for a discussion with the family. I think that's the stage at which we lose many more opportunities for transplantation.

Ms. Elizabeth Myles: I would agree with that as well.

According to the report that was done in 2014, one in six potential donors results in an actual donor. Certainly, there's a discrepancy there and certainly a variety of reasons that can account for that.

As we mentioned before, a family veto can be a stumbling block along the way as well, and there can be variations in that depending on the province. It can be as high as almost 50% in the province of Manitoba.

The Chair: Your time is up.

Mr. Ziad Aboultaif: May I allow...?

The Chair: Go ahead.

Mr. David Hartell: If we look at what we can do at the national level, considering the provincial and federal jurisdictions, I think we have the right elements already in place in this country. I think we just need to support and enhance these resources. Canadian Blood Services is the group that can set the national policy and can do the coordination across the country between the different provincial organizations to ensure that everyone is well supported and that we strengthen interprovincial allocation and sharing. It has the resources and the different programs in place. We just need to ensure that these are sustained and well supported and that we have an independent, national research organization that provides the innovation and the new technology to be able to strengthen our organ donation system and improve long-term outcomes for transplant recipients.

The challenge—and I think Dr. Kneteman and Dr. West brought this up as well—is that both of these systems are not sustainable and currently do not have a long-term strategy. I think this is a role that the federal government can play, and this is the leadership that can come from the federal system to ensure that the national research structure that we've created doesn't disappear and that Canadian Blood Services continues to be empowered to provide a leadership role and bring the provinces together.

The Chair: Thanks very much.

Now we go to Mr. Scarpaleggia.

Mr. Francis Scarpaleggia (Lac-Saint-Louis, Lib.): Thank you very much.

I apologize in advance if some of these questions seem a little simplistic or naive. I'm subbing here today, and I wasn't here for the first part of the study. I wish I had been, because this has been an extraordinarily fascinating discussion.

I think I need to get some terms straight so that I can better understand. For example, what specifically does a donation physician do? Is that the surgeon who does the transplant, or somebody who studies whether the organ is healthy and can be used, or studies the criteria for a match? What precisely does a donation physician do?

● (1705)

Dr. Lori West: We can probably both add to this, but a donation physician.... Oftentimes, if there's someone in an intensive care unit who could become an organ donor, there's a bit of a tête-à-tête or a potential conflict such that the critical care doctor—who's trying to save that patient's life—cannot really ethically be involved in issues related to management of this individual as an organ donor. There's a line here.

The critical care person taking care of that patient needs to back away and let a new person come in. This is the donation specialist, who learns and takes care of how to actually provide medical support for someone who is now deceased by law, if they meet brain death criteria, but who needs to have clinical decisions made as to the right thing to do to support the organs that are going to be used for transplantation, that are going to be donated for transplantation. That's a different kind of specialist.

Maybe Norm wants to comment as well, but that's what we mean by "donation specialist". It's a very important distinction in the process through which an individual becomes a deceased donor.

Dr. Norman Kneteman: A donation specialist can be a nurse or a doctor. In this situation we're speaking specifically about donation physicians and so, as Dr. West has mentioned, that individual will have part of their salary, basically part of their funding, for this separate responsibility. The majority of these physicians are actually critical care doctors during most of their working day, but they will also be, maybe for one day a week or whatever, donation specialists.

If there's no donation going on, they may take part in educational activities for other physicians in the hospital. They may take part in the review of medical records to look for missed opportunities for donations. They'll do these other jobs that are critical for donation, and in the event that a potential donation happens, they will be the individual, as Dr. West has said, who will come in and take over when a decision is made to go forward with donation. Again, the individual who has been caring for that patient in life does have a relative conflict in terms of the donation side of the equation.

Mr. Francis Scarpaleggia: In your estimation, roughly speaking, what percentage of hospitals across Canada would have somebody within the hospital who could fulfill this particular role? I would imagine that would be a key obstacle to...because somebody would have to do it before a donation could be made, I would think.

Dr. Norman Kneteman: I think every hospital in the country would have someone who could do this. It's a question of whether they have someone who's funded to do this.

The recommendation is that every hospital that has an active critical care unit should have someone. In fact, in jurisdictions like Spain and such, that's actually the case, so they have many more of these sorts of physicians. Whenever the potential for donation comes up, there is someone who is knowledgeable in the area and comfortable in the area to take the lead in that process.

Mr. Francis Scarpaleggia: It came up a little while ago. Let's say a facility does have that position; how does it work in practice, in real time? If someone is deceased and there's a sense that certain organs are healthy enough, how is contact made with potential recipients? I can't visualize how this whole process works.

Dr. Norman Kneteman: It is a complex process, with many simultaneously moving parts. That's one of the reasons we need specialists in the area, and we have the support of donation coordinators, who help with much of this.

In fact, the notification to the organ procurement organization would usually go first to an organ donation coordinator, who would then contact the individuals in the different parts of the system. First we have to understand whether the potential donor has actually progressed to being declared dead or is a potential donation after cardiac death. Those are two different situations.

They may then talk with the potential recipient transplant teams, the physicians and surgeons, who will decide if the organ being offered is suitable to be transplanted. If it is, then the system has to search through the wait-list to find the person who is the best match or is at the top of the list.

From then, there is the organization of the actual recovery of the organs from the donor and the logistics for the transport of those organs to the different centres where the transplants are going to be carried out, which may be across the country.

There are many, many moving parts to be coordinated. All of them, however, are critically important, and that's why the system has to be highly functioning.

● (1710)

The Chair: I'm sorry, your time is up. Those were excellent questions and excellent answers, but your time is up.

Now we have to go to Mr. Lobb.

Mr. Ben Lobb (Huron—Bruce, CPC): Thank you very much.

Again, I've probably missed this, but how many organ donations are there a year in Canada?

Dr. Lori West: How many total donations are there per year? We had about 800 deceased donors last year and just over 500 living donors.

Mr. David Hartell: That resulted in over 2,000 transplants because of those donors.

Mr. Ben Lobb: That can't be for the whole country, though.

Dr. Lori West: That's the whole country.

Mr. David Hartell: It is.

Mr. Ben Lobb: Thirteen hundred?

Dr. Lori West: That's right. That's it. I know—it's amazing.

Mr. Ben Lobb: Yes.

Here's a question then. Give me your ethical perspective on this. Is it unethical to provide a tax credit or to pay people to donate their organs after they're deceased or to put that into their.... Is it unethical to do that? I don't know.

Dr. Lori West: This is a matter of great discussion in the transplantation world worldwide. What are incentives, are they really unethical, and can you look at them in certain ways? Can we look at disincentives rather than incentives? It's very complicated. It's extremely complicated, so your question about whether it is ethical can't be answered in a simple way.

There are many things, though, that we can do to remove barriers and obstacles to transplantation. Is it ethical to make a living donor pay for their own surgery for this system, which will save the system thousands and thousands of dollars by the individual recipient having received a transplant? There are many ways that plays out through this entire process.

Do you want to add anything there?

Dr. Norman Kneteman: A blatant payment to someone to come and donate a kidney is, to me, in our system, unethical and is not supported, and I don't think any transplant program in Canada would be onside with doing that.

However, as Dr. West has pointed out, there are a bunch of other situations that are in the middle of the line. What do we say if the potential donor, in fact, a relative, for example, lives in the United States and has to travel across international borders, take time off work, incur costs, and rent an apartment in the Edmonton area while their family waits for them to donate? There are a whole bunch of disincentives where they have to pay money out of pocket. Certainly, for those sorts of things, I think there is increased movement to finding ways, and different provinces have different levels of execution of this whereby they will compensate the potential donor for those sorts of costs.

Mr. Ben Lobb: I have never had to make that choice, and hopefully I will never have to make that choice, but I can see some people saying, "Poor Jimmy was in a car accident, and we have to make a decision here. If there is $10,000 to help with his funeral costs, let's just go ahead and do it." Maybe they hadn't thought about it before. I don't know. I'm sure some people will gasp at even thinking like that.

Dr. Lori West: These are some of the very things that are being considered, and they're not only financial.

Dr. Norman Kneteman: There are certain jurisdictions, certainly in the U.S., in which that sort of payment is made to cover funeral costs and such, but again, it's a question of how far you stretch it. At the base, there is an ethical contraindication to straight payment of cash for an organ.

Mr. Ben Lobb: Yes, and certainly, your reference to a kidney, I think, was perfect, well in line with what would be considered unethical, for sure.

Dr. Lori West: There are also non-financial issues such as a different place on the wait-list. In Israel, if you donate an organ, your relative on the wait-list gets a preferential boost up the wait-list, so there are lots of ways of thinking about this.

Mr. Ben Lobb: You talked about research, and that's vitally important too. In 2015, I and a few other people worked with ALS Canada and with the minister at the time, and there was a round of multi-year funding to put it all together so that they had, I believe, seven years of consistent funding, and it really put it all together.

It seems to me as though this would also be appropriate at this time. I wouldn't want to put a number to it, but certainly, with the Canada Brain Research Fund, they match money, and it would seem as though this would be something as well on which the Government of Canada would work with different groups to pool money together so it all consisted in pulling in the same direction. Maybe that would be something that could come out of this.

● (1715)

Dr. Norman Kneteman: It would be a huge help. As I mentioned, and as Dr. West mentioned as well, we have many of the pieces in place to do these jobs well, but at the present time, for example, in Canadian Blood Services, the section charged with this goes back every three years to write another request to the federal-provincial-territorial ministers conference for funding. How much is going to come, and whether any is going to come, is never known for sure, and that's a very difficult way for a national organization with such an important job to be operating. It seems that you just get the last tranche of money and, within a year, your focus is on looking at how to get funding next time rather than how to do the job that we're basically required to do.

Mr. Ben Lobb: I'm sure ALS Canada would be happy to provide what that meant to them, but my time is up.

Dr. Norman Kneteman: I'm sure Dr. West feels that it's exactly the same situation as well.

Dr. Lori West: You've provided a strategy in your documents that proposes exactly that pathway forward. Your support on that would be very helpful.

The Chair: Thanks very much.

Now we go to Mr. Ayoub, so it will probably be in French.

Mr. Ramez Ayoub (Thérèse-De Blainville, Lib.): Yes, it's going to be in French.

Thank you.

[*Translation*]

First of all, thank you very much for being here today. This is an extremely interesting issue.

Ms. Blackstock, your testimony was truly captivating, and it is more than welcome. I was very touched by it.

We have begun our study of the issue of organ donations and transplants. I do not want to be negative, but I have one remark.

I would like to know what keeps you up at night. You are professionals with many years of experience in your field. I realize that working in isolation is problematic. The provinces and the organizations are working separately. I understand from your presentations that there are many organizations. However, I've noticed a lack of efficiency in the results.

Personally, I'm all about results. If managers look at these results over a long period of time, they would ask themselves if any major progress has been made. The percentages are important because there are few donors. In Quebec, we have 173 donors. One is always better than none, but, if some were to be added to the list, then the percentage would soar.

Canadian Blood Services is responsible for providing leadership in Canada. I've already met some people from this organization, and I look forward to meeting them again. Does this leadership translate into public awareness? Canadian Blood Services has not been involved in any public awareness activities for a long time. Yet this is part of their responsibilities.

How do you see this? What is the trigger?

I've already taken two minutes to ask you this very broad question, and I only have five minutes. Any of the witnesses can answer.

[*English*]

Dr. Norman Kneteman: I'd first like to apologize. It took me a few minutes to get to the English translation, so, unfortunately, I missed the question.

[*Translation*]

Mr. David Hartell: I can answer.

Seeing all of these organizations here working together gives me hope. This is recent. When the Canadian national transplant research program was created, it was the first time that we brought researchers working on organ donations together with those working on transplants. Normally, these are two separate fields, but we realized that we achieve progress by working together.

The document we gave you lists all the partners we have brought together, because transplantation affects many fields. It affects the Kidney Foundation of Canada and the Canadian Liver Foundation. It's really by working together that we can improve the situation. Canadian Blood Services is one of our most critical partners. It's by working together that we can give—

● (1720)

Mr. Ramez Ayoub: It's well known that we achieve more by working together.

You're here, we're together, and we're talking. But where is the leadership, and where are the results? Apart from getting together and writing reports, that is. According to Mr. Kneteman's presentation, many reports have been written over the years. These reports aside, what measures have been taken?

You say that you need ongoing funding, but how can we get to 200, 800 or 1,000 organ donations? How can we increase the number of organs donated and the number of lives saved? How can we shorten the waiting lists and lower the number of people who die every year waiting for organ donations? Where are these results?

Mr. David Hartell: We would be glad to share our results as well as all the progress we've made in the last five years. We also need to consider the new technology that is changing the way transplants are done in Canada today, not tomorrow.

Our goal is to eliminate, 10 years from now, the wait time for new transplants. It really has transformed.

Mr. Ramez Ayoub: I would like to hear from Mr. Kneteman on this issue.

[*English*]

Dr. Norman Kneteman: I did show slides that illustrate the fact that, over the last decade, we have gone from that very discouraging flat line stuck at 15 donors per million to an increase in Canada by 50% over the last 10 years. I think we also recognize that although that's a very important accomplishment, there is much more that can still be done.

That work has been done by federally and provincially and by all the different agencies that had a role in that. In fact, there is ongoing work and co-operation. For example, Ronnie Gavsie, who is the head of Trillium Gift of Life from Ontario, sits on our organ donation and transplantation expert advisory committee for Canadian Blood Services and provides input from her expertise in her province in terms of what's working, what's effective, and what we should do.

There are ongoing supports between the different systems, and we would like to see those strengthened and basically carried forward, because that national interaction is critical. With the system of health care and government that we have in Canada, it's not going to be just one national system that runs everything. Basically, this is a provincial responsibility, but there are many jobs that just aren't going to be done by a provincial agency because they involve sharing organs across the country, which happens not infrequently, and putting these sorts of strategies in place in all of our provinces rather than just some.

[*Translation*]

Mr. Ramez Ayoub: What's troubling—

[*English*]

The Chair: Your time is over.

Mr. Ramez Ayoub: My time is up?

The Chair: Your time is up—by quite a bit.

We will transplant over to Mr. Davies.

Mr. Don Davies: Thank you.

Dr. West, you had a reference in your opening remarks to the issue of organ trafficking and tourism. Can you give us an idea, broadly speaking, of the scope of this?

Dr. Lori West: Do you want to take that, Dave?

Mr. David Hartell: The scope of organ trafficking is one that I think, on the positive side, has decreased lately. It is still a problem. There are many countries in the world where they do illegal organ trafficking. It is still a problem that we need to address, but at least it's decreasing. One of the reasons it's decreasing is that we're seeing advances in our own deceased-donation programs and living-donation programs here. The kidney paired-exchange program in Canada is having a big impact on that.

In terms of what we need to do, I'm happy to share this with the committee. We commissioned a study with international researchers, legal experts, and transplant experts to look at what we could do to help fight the organ trafficking and medical tourism problem in Canada. One of the main recommendations that came out of the study is that we should be tasking physicians with doing mandatory reporting on their patients who have received transplants from another country.

● (1725)

Mr. Don Davies: Can I interrupt for second? I'm trying to get a handle on what the extent of the scope is in Canada. Do you have any idea how many Canadians may be engaging in this?

Mr. David Hartell: That's the problem. By implementing reporting, we would get a proper sense of the problem. Right now it's hard to understand how many patients are going out. Because of doctor-patient confidentiality, we're not capturing this information.

Mr. Don Davies: I don't mean to be cheeky, but how do we know that it's decreasing then?

Mr. David Hartell: What I've been told by my colleagues in the field is that they are seeing—

Mr. Don Davies: Is that the general sense?

Mr. David Hartell: Yes. The general sense is that there is less of this. I don't want to diminish the problem, but it is something on which I think there is a role for the federal government to play. I'm happy to share the recommendations with this committee.

Mr. Don Davies: Dr. West, I want to get a very clear recommendation from you. How much money is needed from the federal government to keep this research program going?

Dr. Lori West: At the moment, the structure of the program is about $40 million. We have put in place a structure that's now going to be decreased to about $3 million. In order to keep this program going, we really need to recapitulate what we had when we built it, because we have much bolder visions now to really solve these problems.

We would guess that, to put a figure in place, it would be in the order of $60 million over five years to move it forward for another five years.

Mr. Don Davies: I'm probably running out of time.

The Chair: There's time for just one little one.

Mr. Don Davies: Dr. Kneteman, you mentioned creating a national database. If you could create the national database, what would it look like?

Dr. Norman Kneteman: We have many of the elements there. The Canadian Transplant Registry is actually in place, and it is a system to bring this information together. All of the different organ organizations—the kidney specialists, liver specialists, etc.—have already come together and decided which elements are the minimum datasets to be able to follow this effectively. The challenge is that we need to fund the activity—people—to basically get that information into the database from every transplant centre and every donation centre in the country. Right now there is no funding for that. We also need to make it mandatory, because otherwise it just won't show up.

Mr. Don Davies: Thank you.

The Chair: Now, that completes our official round, but I can't help but think that Dr. Eyolfson might have a question. If he does have one, I would ask for unanimous consent to have him ask a question.

Do you have a question you want to ask? Is there anything burning?

Mr. Doug Eyolfson (Charleswood—St. James—Assiniboia—Headingley, Lib.): No. Everyone has asked such great questions. I'd just like to say—

Mr. Don Davies: Mr. Chair, I would just say that I know he's a marathon runner. I want first dibs on his lungs.

Mr. Doug Eyolfson: I have just a comment. I appreciate the change now to having a separate physician do this. I'm an emergency physician by training. I did this for 20 years. A number of years ago, we had to have this conversation, and we—the ones who were providing care—were the ones having this conversation with families. It was a very difficult thing to do. If you can imagine, you have a 22-year-old with a devastating gunshot wound to the head. You have shocked family members. You are giving them the worst news, and then you say, "Oh, by the way, can we have his organs?" It is a very difficult place to be in. A change from that is welcome. I also have experiences from the past when sometimes we would lose organ donors because there was just loss of coordination depending on what time of the night they came in and who was available. Time would pass and you would realize this just wasn't going to happen. It was a tragedy every single time. So, all I have to add is to thank you all for your—

Yes, Dr. West.

Dr. Lori West: We also need to consider and remember that this country, the geography, is huge and we can't focus only on the cities and the urban areas where deaths occur. Highway deaths in the remote areas need a special approach. It needs to take into account these.... Alberta is one good example. It can't just be Edmonton and Calgary. We have to look at Red Deer and Lloydminster. I think that's one of the places where creative thinking can add to how we approach these.

Mr. Doug Eyolfson: Absolutely. I flew for air ambulance for 13 years. It was a fixed-wing program, and we would do medevacs that were a two-hour, one-way flight by jet. We're talking about some very remote areas. You're right. Some of those cases were potential organ donors, and I think we need to make sure that it isn't.... As I say, you shouldn't have organ donors in just the big cities because they're already rare enough; you don't want to lose potential donors.

I thank you all for your efforts in this.

● (1730)

The Chair: Thanks very much. I often say we have the best witnesses and panellists of any committee in Parliament. You certainly reinforced that argument today. You have given us a lot to work with and a lot to think about.

I want to thank Mr. Aboultaif for telling us his family's story, because there are 338 members of Parliament and we're just people. We experience the same things that everybody else does. People kind of forget that we're people sometimes, but we are, and to hear that was helpful.

I want to thank you all very much. We're going to put a lot of thought into this. We were going to give drafting instructions, but I think we should all think about this a lot and talk about this at another meeting later on, and try to make a difference, if we can, in our report.

Thanks very much, everybody, for your comments.

Dr. Lori West: I've already said we're happy to continue to be engaged, if that's helpful to the committee. We know these are tricky and complex issues.

The Chair: You said earlier—and I wrote it down—it is a complicated landscape. But it's about the simplest landscape we deal with, as far as a solution is concerned. You know, we talk about all kinds of things at this committee—opioid crisis, post-traumatic stress—and we just really don't know what to do. However, if we can raise public awareness and professional awareness and get a little money, you know, it will save lives. So it's actually the simplest landscape, I think.

Anyway, thanks very much.

Now, we're going to take a little break before we start all over again in the next meeting. We're going to take 15 minutes.

The meeting is adjourned.

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